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Improving psychological outcomes for orphans living with HIV in Tanzania through a novel intervention to improve resilience: findings from a pilot RCT.

Abstract

Parental death, poverty and HIV are associated with poor mental health for orphans in sub-Saharan. This study aimed to evaluate a theory-based intervention for orphaned children on HIV treatment in Tanzania, in terms of feasibility, acceptability and preliminary outcomes.

A pilot RCT with nested focus group discussion (FGD) allocated 48 children to usual care or residential “Memory Work Therapy”. Children completed validated outcome measures at T0 (baseline), T1 (2 weeks following intervention) and T2 (9 weeks from T0).

40% of eligible children assented. T1 intervention effects were found on all total measures: Brief Symptom Inventory $d=0.99$, $p<0.001$; Rosenberg Self Esteem Scale $d=0.65$, $p=0.001$; Strengths and Difficulties Questionnaire $d=0.64$, $p=0.002$; Self efficacy questionnaire for children both ‘*social*’ and ‘*emotional*’ subscales, $d=0.54$ $p=0.008$ and $d=0.63$ $p=0.002$ respectively.

At T2, significant effects remained for all measures and SES effect increased from medium to large ($T1=0.65$, $T2=1.33$). FGD data revealed that children valued a calm environment that provided their basic needs and enabled them to reflect, highlighted support resources, and strengthened their ability to recognize personal skills.

The intervention has strong feasibility and acceptability, with no attrition or missing data. Memory Work Therapy has high potential effect size and should be tested in a fully-powered trial.

Clinical trials.gov registration number NCT02180750.

Keywords: children, HIV, resilience, psychology, self-efficacy

Background

There were an estimated 1.5 million children living with HIV in sub-Saharan Africa during 2015 (UNAIDS), and 56,000 new infections (UNAIDS, 2016). UNAIDS/UNCF estimates that 12% of all children in sub-Saharan Africa are orphans (*Africa's orphaned and vulnerable generations. Children affected by AIDS.*, 2006), and that 12 million children have lost one or both parents to AIDS.

The clustering of risk factors in low and middle-income countries (poverty, maternal psychological functioning, orphanhood and stigma) greatly increase the risk of poor mental health among children and young people affected by HIV (Abubakar, 2014). The indirect effects of parental HIV infection and possible death are associated with children's poorer physical and mental health, education and safety (Desmond et al., 2014). Parental HIV infection and death is associated with greater depression, anxiety and post-traumatic stress in children (Sherr and Mueller, 2009). Orphanhood among HIV-infected children is associated with worse psychological distress, and with poorer social outcomes (Guo, Li, & Sherr, 2012).

The care and support of these children also pose enormous challenges to their professional caregivers, who identify particular difficulties in supporting grief, and a lack of resources to explore and manage bereavement among children and young people (Demmer, 2006). Although it is suggested that orphaned young people with HIV-related bereavement avoid their grief emotions (Popoola and McHunu, 2015), there has been a lack of outcomes-focused intervention research among bereaved children and young people in Africa (Taylor, Thurman, & Nogela, 2016). Support for the patient, family and staff needs in relation to grief has been identified as a priority for health systems strengthening among HIV services in seven African countries (Alexander et al., 2012). The presence of a trusted adult and social support is protective for psychological outcomes among orphaned children affected by HIV (Barenbaum and Smith, 2016). In turn, improved mental health is associated with

reductions in internalized stigma among people with HIV (Pantelic, Shenderovich, Cluver, & Boyes, 2015).

Given the lack of prior outcomes evidence, the trial processes and potential effectiveness should be determined prior to a definitive trial. This study aimed to evaluate a theory-based intervention compared to usual care for orphaned children on HIV treatment in Tanzania, in terms of feasibility, acceptability and preliminary outcomes.

Methods

This study used a pilot randomized wait list-controlled trial design, with 2 parallel arms and nested focus groups, conducted in Dar-es-Salaam, Tanzania.

Clinical trials.gov registration number NCT02180750.

Sampling and ethics

Inclusion criteria were fully orphaned children (i.e. both parents had died of any cause) between the ages of 14-18 (given that in the African context 'children' includes people who are 18 years old)(Deacon and Stephney, 2007), under HIV care and currently on antiretroviral therapy (ART).

Exclusion criteria were having previously received the intervention, having poor physical or mental health that precluded attendance, having no adult caregiver to give consent, or insufficient Swahili literacy to take part in the intervention activities. Children were recruited over 8 days at a weekly pediatric clinic and service user meeting. Caregiver written consent and child assent were taken following the researcher reading aloud the information sheet to those eligible. To meet the aims of this pilot trial we aimed to recruit 48 children, as the group runs for a maximum of 24 children and therefore we would be able to run a full intervention with wait-list control. Any child who declined participation was able to continue receiving all existing control (standard care) services.

Ethical approval was granted by the National Institutes for Medical Research Tanzania (ref NIMR/HQ/R.8a/Vol.IX/1481).

Allocation

Following T0 data collection, children who entered the study were randomly allocated by the study lead researcher (EM) 1:1 to intervention or a wait list control using concealed slips of paper, which the child took from a tin. This was stratified by gender in a ratio of 1:1 female:male.

Intervention

A literature review appraising mental health among HIV-affected children in sub-Saharan Africa concluded that interventions should take a more “culturally-relevant and strengths-based” approach (Skovdal, 2012). It concluded that more “community-oriented and resilience-enhancing research” is needed. The focus on locally-developed psychological interventions is crucial, given evidence that practitioners in Africa have hesitance regarding the adaptability of Western interventions (Kane et al., 2016). A further review of pediatric HIV psychosocial interventions concluded that both building self-reliance and increasing uptake of community resources are needed (Amzel et al., 2013). This should be individualized, given that although bereavement may share common cultural processes, cross-cultural research has demonstrated that support mechanisms should recognize the individual’s response (Cowles, 1996). The intervention drew on the ecological model which describes how children’s resilience can be enhanced by building on their own strengths and capabilities, building peer relationships, and community-level support (Masten, 2001). to build Resilience is defined by the APA “as the ability to adapt in the face of adversity, tragedy, threats or significant stress. It involves behaviors, thoughts and actions that can be learned and developed in anyone” (APA)) The conceptual model of

the resilience intervention builds on internal assets of the child, family and community resources (Li, Chi, Sherr, Cluver, & Stanton, 2015). Within the intervention, the goal of memory work therapy (MWT) is to create a “safe space” in which an orphaned child can explore their life story in an individual or group setting. Memory Work draws on Narrative Therapy, which helps people to find and live out empowering parts of the stories that make up their lives. Narrative Therapy and MWT aims to identify strengths and “empowering plots” (*Memory box manual: a facilitator's guide.*, 2007). A qualitative evaluation of the Memory Book Intervention component of the present intervention in South Africa found it enabled grief resolution (Braband, Faris, & Wilson-Anderson, 2014). The novel integration of these intervention elements aims to build resilience through identification and enhancement of individual skills, personal and community resources as described in the theory of Masten (above). A recent systematic review found no studies that reported evidence of effectiveness for this intervention or its components and called for further trials in this field (Skeen et al., 2017).

The intervention was conducted over a five-day residential camp, and included Memory box, Memory book, Tree of life and the Hero (Active Citizen) book (see Table 1). These activities were delivered to children during groupwork activities that included one-to-one support while activities were underway. Each day ended with 90 minutes of sports/games (see online supplement for details in Table 5). The camp was free of charge to children, and was delivered by five staff: qualified social workers (n=3), a clinical officer (n=1) and a medical doctor (n=1). Prior to the camp, children and their caregivers were asked if any additional resources would be needed (e.g. additional bed clothes due to bed-wetting, special pharmacological support, food allergies).

INSERT TABLE 1 HERE

Control

Those allocated to control received standard care, i.e. continued access to all medical and support services but none of the specific activities listed in Table 1. The control group members were offered the intervention 6 months after the pilot trial group was delivered.

Data collection

Data collectors were blinded to allocation. Baseline (T0) data collection took place immediately following consent and assent within 2 weeks immediately prior to the intervention. Follow-up was conducted within 2 weeks following intervention (T1, 5 weeks from baseline) and final follow-up 4 weeks later (T2, i.e. 9 weeks from baseline). All participants were allocated a unique study ID that was unrelated to their clinic ID.

Demographic data were as follows: age (years), gender (male/female), education (highest year), number of people in household, head of household, CD4 (cells/ μ L blood).

The self-report outcome measures address resilience (ability to do things better) and psychological outcomes (symptoms, self worth, and mental health).

The Brief Symptom Inventory (BSI) is a 53-item self-report inventory of psychological symptoms. Answers are on a 5-point scale, from 0 = "not at all", to 4 = "extremely".

The BSI has high internal consistency (Cronbach's alpha: 0.71-0.85), test retest reliability, and convergent, discriminant, and construct validity. It has been successfully used among children with HIV (New, Lee, & Elliott, 2007), and has construct validity across ethnic groups (Hoe and Brekke, 2009).

The Rosenberg Self Esteem Scale (SES) is a 10 item Likert scale with 4 response levels for each item (Rosenberg, 1965), and is a unidimensional measure of self-worth. It was developed among adolescents, and has good alpha reliability (0.72 to

0.90) (Mueller et al. 2011). It has been successfully used among HIV-infected adolescents in East Africa (Nöstlinger, Bakeera-Kitaka, Buyze, Loos, & Buvé, 2015). The Strengths and Difficulties Questionnaire (SDQ) is one of the most commonly used measures of mental health in children and young people, and has been translated into more than forty languages (Goodman, 1997). The 25 items each load onto one of five subscales: Emotional Symptoms, Conduct Problems, Hyperactivity, Peer problems and Prosocial Behavior. The Youth self-report version used in this study has been validated for self-completion in adolescent populations and has a reported alpha coefficient of 0.82 (Mueller, Alie, Jonas, Brown, & Sherr, 2011).

The Self-Efficacy Questionnaire for Children (SEQC) is a 24-item Likert scale that measures the child's view on how he or she could do things differently or better (Muris, 2001). The tool provides two subscales: social and emotional. The child ranks each item 1-5. Cronbach's alpha for the adapted scale with this population is 0.758 (Mueller, et al., 2011).

Tools were forward/backward translated into Swahili, and researcher-administered. A focus group discussion (FGD) was conducted 1 week after the intervention. Twelve intervention participants were purposively sampled on the characteristics of gender and age. FGD were conducted in Swahili by the study researchers. One research assistant acted as moderator, while another was a rapporteur collecting participant views. A third research assistant operated and recorded the discussions on a digital recorder. The semi-structured topic guide addressed the participant views and acceptability on content, format, delivery and mechanisms of action to achieve the intended outcomes of the intervention.

Analysis

The analysis plan sought to answer the following questions. 1) What is the feasibility and acceptability of the intervention (determined using the % of those approached

who entered the trial, % of missing data, intervention delivery as intended, qualitative focus group discussion data on intervention participation, % of waitlist control participants who chose to attend the intervention after the study) and 2) What is the potential effectiveness of the intervention?

For potential effectiveness, intention to treat analysis of quantitative outcome data was undertaken by a clinical trial statistician (GW) blinded to allocation group.

Findings for both T0-T1 & T0-T2 were derived from truncated regression analysis, adjusting for baseline score and CD4 count. Cohen's D effect size was converted from the standardized regression coefficient (Cohen, 1988).

Analysis of the qualitative FGD transcript was conducted by the lead researcher (EM), who conducted thematic analysis to determine views on the content, process and outcomes of the intervention. This was conducted by familiarization with focus group transcripts, and line-by-line coding by hand to generate themes. For each direct quote from the translated verbatim FGD transcripts, the participant's unique ID number is reported. The initial coding frame was reviewed and agreed with a second author (RH) and interpretation agreed between all authors.

Results

The patient flow through the trial is reported in a CONSORT figure (Hopewell et al., 2008) (see Figure 1).

With respect to feasibility and acceptability, of the n=400 screened, n=126 (31.5%) met the inclusion criteria. Of these n=50 (39.7%) children met the inclusion criteria and gave assent to participate (i.e. 12.5%). One child gave assent, but their grandparent would not consent. One child dropped out of the study after baseline data collection prior to the intervention. Both were replaced to achieve the target sample. All 48 were successfully randomized. No protocol deviations were identified in terms of recruitment, allocation, intervention fidelity or data collection. All of those

recruited also participated in both follow-up timepoints. Of those allocated to control, n=24 (100%) chose to attend the intervention at 6 months.

INSERT FIGURE 1 HERE

Sample characteristics

The sample baseline characteristics are described in Table 2. The mean age was 15.7 years, the majority (n=30) living with their aunt or grandmother, in a mean household size of six people. Visual inspection of the baseline data showed group differences for CD4 count (382.3 cells per mm³ for intervention, 466.3 cells per mm³ for control) and for Brief Inventory Score (mean 382.3 intervention, 466.3 control, i.e. worse score for control).

INSERT TABLE 2 HERE

Person-reported outcomes

All participants completed data collection at T1 and T2, with no missing data at the participant or item levels.

At T1 (see Table 3), significant effects were found for the intervention on all measures: Brief Symptom Inventory, $d=0.99$, $p<0.0010$; Rosenberg self-esteem $d=0.65$, $p=0.001$; Goodman's Strengths & Difficulties Questionnaire total score $d=0.64$, $p=0.002$ with intervention effects on three subscales '*Hyperactivity*' $d=0.43$ $p=0.036$, '*emotional*' $d=0.71$ $p=0.001$, and '*conduct*' $d=0.62$ $p=0.003$, but not for '*peer problems*' and '*prosocial*' subscales; for both subscales of the Self Efficacy Questionnaire '*social*' and '*emotional*' $d=0.54$ $p=0.008$ and $d=0.63$ $p=0.002$ respectively.

INSERT TABLE 3 HERE

At T2 (see Table 4), the lack of effect for '*peer problems*' subscales persisted on The Goodman's Strengths and Difficulties Questionnaire, and while the effect on the '*conduct*' subscale was lost, an effect for prosocial was identified at T2 that was not present at T1. All other significant effects remained.

Interestingly, while the effect size (Cohen, 1988) for the Brief Symptom Inventory remained large (T1=0.99, T2=0.80), the Rosenberg Self-Esteem Scale increased from medium to large (T1=0.65, T2=1.33), the Self-Efficacy subscales of ‘*social*’ and ‘*emotional*’ both increased from medium to large (T1=0.54, T2=1.10 and T1=0.63, T2=0.26 respectively). Goodman’s Strengths and Difficulties Questionnaire effect size remained medium (T1=0.64, T2=0.76).

INSERT TABLE 4 HERE

Qualitative FGD views

-Child sample characteristics

For the 12 children who attended the post-intervention FGD, mean age was 16.0 years, and 50% were female. All lived with a relative, the majority (n=7) with an aunt or grandmother.

-Child views on the intervention

Firstly, children discussed the environment and meeting of basic needs that were seen as positive, and gave them a context in which to reflect:

“The environment and games, it was very quiet and most of the people there are very serious, for the first time I realize that there are places in the world that are quiet and peaceful” (Male, aged 16)

“I also liked the food and drinks and the discussions, we rarely have drinks home”
(Female, aged 15)

“I discussed a lot of ambitions. The facilitators helped me reflect about my life, I made a memory box and kept my late father’s picture” (Male, aged 14)

An important process was the ability to identify existing support and resources:

“I drew a dress that was given to me by my guardian, I remember I was very happy that day, I discovered the hero of my life and also discovered that I am a hero even though I am living with HIV and AIDS. Drawing the tree of life was a journey in my

life. I had the opportunity to acknowledge the support I am receiving from different people in my life” (Female, aged 18)

“I discovered the relatives that surround me, I discussed with my friends the different problems that I face, we exchanged our books and drew half of the faces, we ate good food, and we played games” (Female, aged 17).

Being able to identify social resources was described alongside being able to reflect on their past challenges

“The tree of life, club of life I understand my surrounding and friends, met different friends and did played different games, I had time to think about my past in an easier way” (Female, aged 17).

Benefits were not only in terms of identifying their individual skills and strengths, but in recognizing what they had in common with others;

“I learnt a lot from each one of them and I now realize the different talents that I have. I thought I was the only one living with an old aunt” (Female, aged 14).

No unintended harms or consequences were reported.

Discussion

We present the first feasibility, acceptability and outcomes-based evaluation of Memory Work Therapy, a novel theory-based intervention to improve psychological resilience among bereaved children on HIV treatment in sub-Saharan Africa.

This novel study has shown that the intervention has strong feasibility and acceptability and that recruitment and retention in the trial were high, with no attrition or missing data. Importantly, Memory Work Therapy appears to have a high potential effect size on the outcomes we measured, although this should now be tested in a fully-powered trial.

We note that despite the trial not being fully powered to detect a statistically significant advantage for the intervention on the outcome measures, we were able to detect a statistically significant advantage for the intervention on all outcome measures, with an exception for the “peer” subscales on the Goodman’s Strengths and Difficulties Questionnaire. Importantly, the effect size at final follow-up remained large for the Brief Symptom Inventory, increased from medium to large for the Rosenberg Self-Esteem Scale, increased from medium to large for both subscales (*‘social’* and *‘emotional’*) of the Self-Efficacy Questionnaire, and increased but remained medium for the Goodman’s Strengths and Difficulties Questionnaire. An effect was detected at T2 that had not been present at T1 for the “prosocial” subscale of the Strengths and Difficulties Questionnaire, which suggested a skill development over time.

The qualitative data confirm that the intervention processes achieved the outcomes that were theorized from the integration of the components, i.e. children identified their community resources, felt able to recognize their family resources, and felt empowered to use their individual strengths. The format of the intervention was also

important to participants- i.e. that children were taken away to a “camp” environment with food, a quiet space and facilitation that enabled them to reflect and build resilience. This suggests that the programme of components should be delivered in an environment away from their home setting to achieve the results we observed. With respect to study limitations, firstly we have not conducted an economic evaluation to model the cost-benefit of delivering this intervention. Second, we note that the nature of the intervention, i.e. a residential model, is most suitable for those without high care needs and for settings with organisations capable of providing the resources required for a residential intervention. Third we acknowledge that acceptability of this intervention may have been higher in this setting due to the prior history of its delivery, and positive feedback from prior attendees may have influenced our sample in terms of uptake and outcomes. Fourth, we do not have quality control data on delivery and we would recommend this for subsequent evaluation and implementation study (Moore et al.).

This intervention is theoretically-derived, it is feasible to recruit and retain into a randomized controlled clinical trial, and it offers potentially medium to large effects. We propose that all interventions delivered by care and support agencies should be subjected to rigorous evaluation to ensure that they are warranted in terms of outcomes, and now our pilot objectives are met this intervention should now move forward to a fully powered trial.

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Conflict of interest

The authors state that they have no conflict of interest.

Access to data

RH confirms that they had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Key points

What's known:

- Orphaned children living with HIV in sub-Saharan Africa have poor mental health and social outcomes.
- Although interventions are recommended that assist children to acknowledge their losses and to identify and utilize their community and family resources, outcome evaluations are rare.

What's new:

- We determined the feasibility, acceptability and preliminary outcomes of a theoretically-derived residential intervention to enhance resilience and improve psychological wellbeing.
- 40% of eligible children gave assent and their caregivers gave consent to enter the pilot trial. For all psychological outcome measures, medium to high effect sizes were found, with no missing data or attrition.
- Children described the benefit of being away from home with basic needs met to enable them to identify their support networks, recognize their personal strengths and to meet other children with similar life experiences.

What's clinically relevant:

- A fully powered trial is now required so that the potentially high effect sizes can be tested, and implementation initiated.

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Figure 1 CONSORT flow diagram

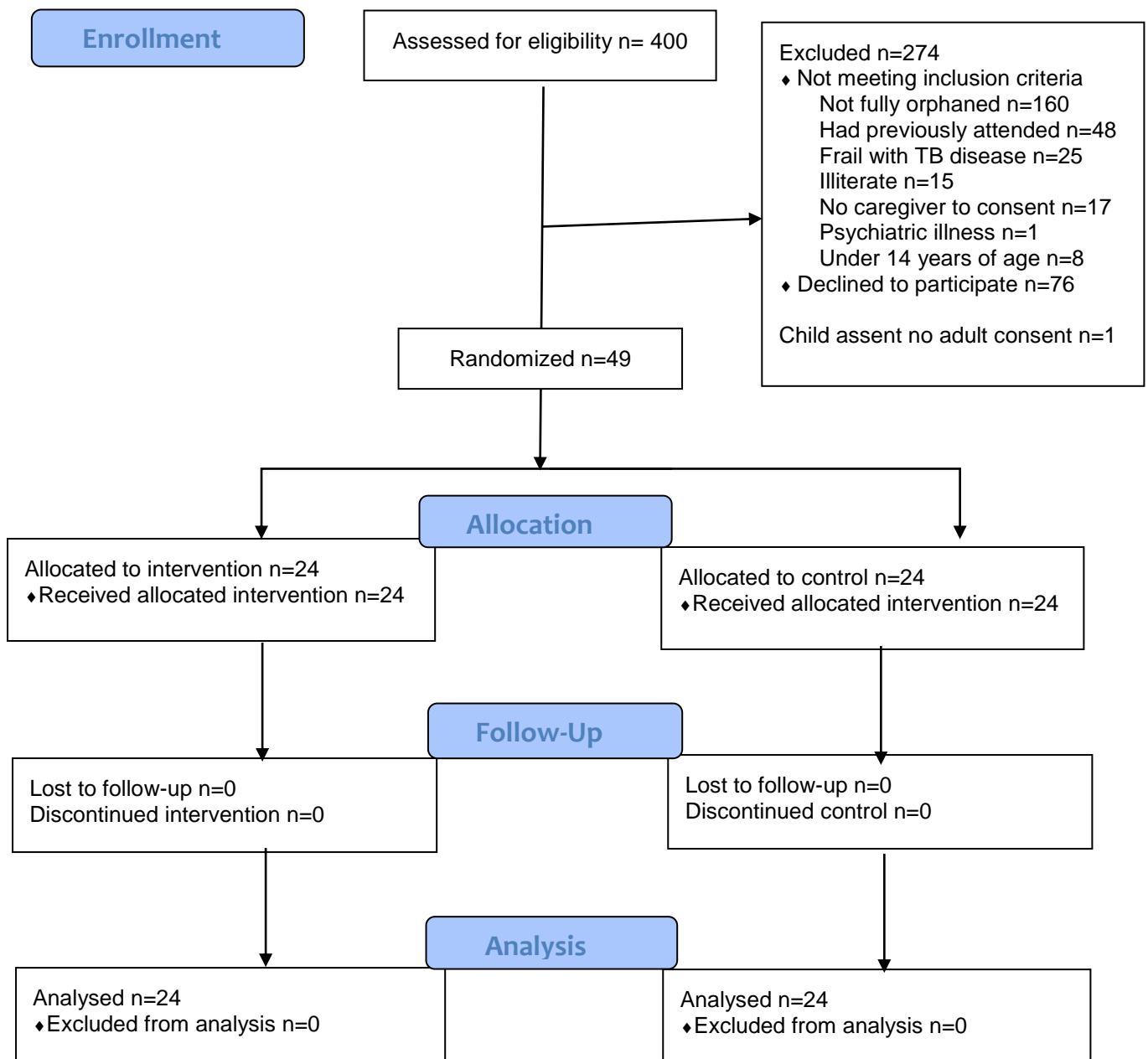


Table 1 Session timetable of MWT

Day	Activity	Objectives
1	Memory Book	To prepare a space to explore life stories through artwork.
2	Memory Box	To help the children find a safe place to keep the MWT book (contains Memory Box, Tree of Life and Hero Book).
3	Tree of Life 1	To create and explore a new story that is not only about pain and suffering but that also notes courage, survival skills, values and hope through artwork.
	Tree of Life 2	To build and acknowledge “a second story” about each child's life. The second story consists of the skills, abilities, hopes and dreams of each child and the histories of these through artwork
4	Hero Book	To help the children find solutions to the personal and social challenges they face through artwork
5	Issuing of Certificates of Participation	Closure of the group and recognition of their participation and achievement.

Table 2 Sample characteristics n=48.

Characteristics	Category	Total n=48		Intervention n=24		Control n=24	
		N	Mean(SD)	N	Mean(SD)	N	Mean(SD)
Age	-	48	15.7 (1.4)	24	15.6 (1.4)	24	15.8 (1.5)
Sex*	<i>Female</i>	24	50.0%	12	50.0%	12	50.0%
	<i>Male</i>	24	50.0%	12	50.0%	12	50.0%
Education*	<i>Form1</i>	10	20.8%	5	20.8%	5	20.8%
	<i>Form2</i>	10	20.8%	7	29.2%	3	12.5%
	<i>Form3</i>	5	10.4%	3	12.5%	2	8.3%
	<i>Form4</i>	5	10.4%	2	8.3%	3	12.5%
	<i>Std4</i>	1	2.1%	1	4.2%	0	0.0%
	<i>Std5</i>	1	2.1%	0	0.0%	1	4.2%
	<i>Std6</i>	2	4.2%	0	0.0%	2	8.3%
	<i>Std7</i>	10	20.8%	3	12.5%	7	29.2%
	<i>Not at school</i>	1	2.1%	1	4.2%	0	0.0%
	<i>Vocational training</i>	3	6.3%	2	8.3%	1	4.2%
Number in Household		48	6.0 (4.2)	24	6.3 (5.1)	24	5.8 (3.0)
Head of household*	<i>Aunt</i>	18	37.5%	13	54.2%	5	20.8%
	<i>CHH</i>	3	6.3%	2	8.3%	1	4.2%
	<i>Uncle</i>	7	14.6%	2	8.3%	5	20.8%
	<i>Brother in law</i>	2	4.2%	1	4.2%	1	4.2%
	<i>Grandma</i>	12	25.0%	4	16.7%	8	33.3%
	<i>Grandpa</i>	4	8.3%	1	4.2%	3	12.5%

	<i>Sister(Adult)</i>	2	4.2%	1	4.2%	1	4.2%
CD4	-	48	382.3 (213.8)	24	466.3 (228.5)	24	298.3 (162.7)
Total Brief Symptom Inventory score							
T0	-	48	78.7 (46.1)	24	63.4 (31.4)	24	93.9 (53.7)
T1			71.6 (44.6)		42.3 (22.5)		100.8 (42.0_
T2			63.6 (49.3)		34.6 (33.9)		92.5 (45.4)
Total Rosenberg self-esteem scale							
T0	-	48	12.4 (3.2)	24	25.5 (5.7)	24	24.2 (7.0)
T1			11.6 (3.1)		13.0 (2.3)		10.2 (3.1)
T2			13.8 (3.7)		16.5 (2.5)		11.2 (2.7)
Goodman's Strength and Difficulties Questionnaire:							
T0	<i>Hyperactivity</i>	48	3.4 (1.6)	24	3.5 (1.8)	24	3.3 (1.4)
	<i>Emotional</i>	48	4.1 (2.4)	24	3.7 (2.2)	24	4.6 (2.5)
	<i>Conduct</i>	48	3.4 (1.6)	24	3.4 (1.7)	24	3.3 (1.4)
	<i>Peer problems</i>	48	3.6 (2.0)	24	3.5 (2.0)	24	3.6 (2.2)
	<i>Prosocial</i>	48	7.8 (1.6)	24	8.1 (1.6)	24	7.6 (1.5)
	<i>Total difficulties</i>	48	14.5 (4.6)	24	14.0 (3.9)	24	14.9 (5.2)
T1	<i>Hyperactivity</i>	48	3.3 (2.0)	24	2.7 (1.6)	24	4.0 (2.2)
	<i>Emotional</i>	48	3.2 (2.5)	24	1.9 (1.2)	24	4.5 (2.8)

	<i>Conduct</i>	48	3.1 (1.8)	24	2.4 (1.1)	24	3.9 (2.1)
	<i>Peer problems</i>	48	3.3 (2.1)	24	3.2 (1.9)	24	3.3 (2.3)
	<i>Prosocial</i>	48	6.2 (2.2)	24	6.3 (2.3)	24	6.1 (2.1)
	<i>Total difficulties</i>	48	12.9 (6.2)	24	10.1 (3.6)	24	15.6 (7.0)
T2	<i>Hyperactivity</i>	48	2.9 (1.8)	24	2.0 (1.3)	24	3.9 (1.6)
	<i>Emotional</i>	48	3.1 (2.6)	24	1.8 (1.3)	24	4.4 (2.9)
	<i>Conduct</i>	48	2.7 (1.9)	24	2.4 (2.0)	24	3.0 (1.8)
	<i>Peer problems</i>	48	3.8 (1.8)	24	3.5 (1.6)	24	4.0 (2.0)
	<i>Prosocial</i>	48	7.0 (2.0)	24	7.6 (1.9)	24	6.5 (2.0)
	<i>Total difficulties</i>	48	12.5 (5.9)	24	9.6 (3.8)	24	15.3 (6.2)
Self-Efficacy Questionnaire for Children							
T0	<i>Social scale</i>	48	25.1 (4.7)	24	25.0 (4.6)	24	25.3 (5.0)
	<i>Emotional scale</i>	48	21.4 (4.1)	24	20.9 (4.1)	24	22.0 (4.2)
T1	<i>Social scale</i>	48	24.8 (6.2)	24	27.3 (6.0)	24	22.4 (5.5)
	<i>Emotional scale</i>	48	21.4 (4.1)	24	24.8 (5.8)	24	19.9 (5.0)
T2	<i>Social scale</i>	48	26.7 (6.3)	24	30.7 (3.4)	24	22.6 (5.8)
	<i>Emotional scale</i>	48	24.6 (6.2)	24	28.3 (5.2)	24	20.1 (4.7)

* The starred items are expressed as n, percentage

Table 3 Findings at T1 n=48

Measure	Subscale	Beta (95%CI)	P value	R square	Intervention effect size (Cohen's d)
Brief Symptom Inventory score	-	-44.98 (-63.10 to -26.87)	<0.001***	0.52	0.99
Rosenberg self-esteem scale	-	2.63 (1.01 to 4.24)	0.001**	0.52	0.65
Goodman's Strength and Difficulties Questionnaire	<i>Hyperactivity</i>	-1.24 (-2.41 to -0.08)	0.036*	0.38	0.43
	<i>Emotional</i>	-2.30 (-3.60 to -1.00)	0.001**	0.51	0.71
	<i>Conduct</i>	-1.53 (-2.53 to -0.54)	0.003*	0.41	0.62
	<i>Peer problems</i>	-0.08 (-0.62 to 0.46)	0.77	0.01	0.06
	<i>Prosocial</i>	0.40 (-0.94 to 1.73)	0.56	0.39	0.12
	<i>Total difficulties</i>	-4.88 (-7.95 to -1.82)	0.002*	0.29	0.64
Self-Efficacy Questionnaire for Children	<i>Social</i>	4.18 (1.08 to 7.27)	0.008*	0.32	0.54
	<i>Emotional</i>	4.94 (1.82 to 8.06)	0.002*	0.36	0.63

*significant at the 5% level **significant at the 1% level ***significant at the 0.1% level

Table 4 Findings at T2 n=48

Measure	Subscale	Beta (95%CI)	P value	R square	Intervention effect size
Brief Symptom Inventory score	-	-46.69 (-70.10 to -23.27)	<0.001 ***	0.43	0.80
Rosenberg self-esteem scale	-	5.12 (3.57 to 6.66)	<0.001 ***	0.66	1.33
Goodman's Strength and Difficulties Questionnaire	<i>Hyperactivity</i>	-1.97 (-2.87 to -1.08)	<0.001 ***	0.61	0.88
	<i>Emotional</i>	-2.20 (-3.53 to -0.88)	0.001* **	0.45	0.67
	<i>Conduct</i>	-0.57 (-1.68 to 0.54)	0.31	0.35	0.21
	<i>Peer problems</i>	-0.56 (-1.55 to 0.44)	0.27	0.40	0.22
	<i>Prosocial</i>	1.24 (0.09 to 2.38)	0.035*	0.31	0.43
	<i>Total difficulties</i>	-5.29 (-8.05 to -2.52)	<0.001 ***	0.33	0.76
Self-Efficacy Questionnaire for Children:	<i>Social</i>	7.29 (4.64 to 9.94)	<0.001 ***	0.60	1.10
	<i>Emotional</i>	8.39 (5.71 to 11.06)	<0.001 ***	0.53	1.26

*significant at the 5% level **significant at the 1% level ***significant at the 0.1% level

Table 5 Online detailed intervention description

Table 5 should be read in conjunction with the following intervention web resources:

<https://www.medicusmundi.ch/en/bulletin/memory-work>

<http://www.repssi.org/Att.aspx?fn=Tree%20of%20Life%202016%20hi%20global%20edition.pdf>

https://www.k4health.org/sites/default/files/M_Box_Manual.pdf

Day 1	Making the book						
	Main Objective: To ensure each participant makes his or own book						
	Item	Specific Objective	Activity	Materials/Place	Method	Time	Remark
	Making the book	To help each child make his or her own book	Making a book that has at least 20 pages to combine the	A4 manila paper of different colours, cotton threads (for	Handcraft	8:30-12:30	NB: This is a skill and attachment development

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https://www.k4health.org/sites/default/files/M_Box_Manual.pdf

			Memory, Tree of life and Hero book contents.	weaving sweaters), 3inch nails (used as perforator for the paper) hammer, colour pencils, pencils, watercolours			activity. Children should not be given readymade books. They should each make their own books
	Lunch break					12:30-14:30	
	Memory book						
	Main Objective: To explore life stories through windows of life						
	Item	Specific Objective	Activity	Materials/Place	Method	Time	Remark
Memory book section 1		To dedicate the book to someone important in the participant's life	Participants discuss the importance of their families and each participant draws an image of an important person in the family and dedicates the book to that person by writing his or her name on the cover of the book. This person could be within or without the family	The book, Marker pens, pencils, watercolours	Writing	14:30-15:00	The child gives a social meaning for the book
		To help the participants express negative feelings about being PLWHA through artwork	Participants discuss sad experiences when they realised they were HIV and AIDS patients and draw the symbol or an image of their sadness on the 1 st page		Discussion/sharing and drawing	15:00-16:30	<i>The first window of life</i> NB: Encourage the participants to reflect on the most important point especially how they cope with that situation. The participant writes this on the next page before going to the next window. This is known as Zooming the window and this may apply to every window
	Tea break					16:30-17:00	
Sports/games	To help the participants to Relaxation	Participants to play in groups	Football and netball, volleyball balls, skipping ropes, personal sports equipment in the volley ground	Playing		17:00-18:30	NB: The activities should not be too intensive and creativity should encouraged
	Dinner and cleaning up					18:30-20:30	
Memory book section 2	To help the participants review and share the best moments of their childhood through artwork	The participants discuss the most exciting moment in their childhood and draw its representation or image	The book, Marker pens, pencils, watercolours	Discussion/sharing and drawing		20:30-21:45	<i>The Second Window of life</i>

	Recreation/dancing and singing					21:45-22:30	
	Bedtime					22:30-6:30	

Day 2	Waking and Clean up					6:30-7:30	
	Breakfast					7:30-8:30	
	Memory Book Section 3	To help the participants discuss and view their different stage of achievement despite living with AIDS through artwork	The participants discuss their achievements from one point to another (Arrow pointing up) by drawing a ladder and indicating the different levels on a different point of achievement on the ladder	The book, Marker pens, pencils, watercolours	Discussion/sharing and drawing	8:30-9:30	<i>Third window of life</i>
	Memory Book Section 4	To help the participants discuss and review different stages of difficulties/challenges as PLWHA through artwork	The participants discuss their difficulties/challenges from one point to another (Arrow pointing down) by drawing a ladder and indicating the different levels on different points on the ladder	The book, Marker pens, pencils, watercolours	Discussion/sharing and drawing	9:30-10:30	<i>The Fourth Window of life</i>
	Tea break					10:30-11:00	
	Memory Book Section 5	To help the participants have more time to discuss the difficulties/challenges and what it means to each of the children of participants	The participants discuss those difficulties/challenges and how they felt in that situation and draw any symbol of that experience	The book, Marker pens, pencils, watercolours	Discussion/sharing and drawing		<i>Fifth Window of life</i>
	Counselling (group or individual) break	To provide 'on the spot' counselling for a participant who may need to reconcile his or her difficult situation	Counselling for some participants who would need individual or group who may need attention from staff/facilitators	Counselling room or place	Counselling	11:00-12:30	There may be some children who could have a posttraumatic reaction when sharing their challenges/ difficulties.
	Lunch break					12:30-14:30	
	Memory Book Section 6	To help the participants share the coping mechanism or resilience	The children discuss and share their coping mechanisms when they faced some challenges and draw a symbol of happiness	The book, Marker pens, pencils, watercolours	Discussion/sharing and drawing	14:30-15:30	<i>Sixth Window of life</i>
Making Memory box							
Main Objective: To help the participants find a place to keep their books							
Item	Specific Objective	Activity	Materials/Place	Method	Time	Remark	
Making the	To help the participant	Making the box	Cardboards, glue, gift papers,		15:30-17:00	NB: The children should	

	Memory Box	each to make a Memory Box in which to keep the book made		stapler, pairs of scissors, watercolours.	Handcraft		not be given readymade boxes. They need to make boxes to build attachment and skill development
	Sports/games	To help the participants to Relaxation	Participants to play in groups	Football and netball, volleyball balls, skipping ropes, personal sports equipment in the volley ground	Playing	17:00-18:30	NB: The activities should not be too intensive and creativity should encouraged
	Dinner and cleaning up					18:30-20:30	
	Naming and how to use the Memory Box	To make final touches to the Memory Box, naming or dedicating the Box and putting in the Memory Book	Checking and improving the Memory Box and fitting in the book and finding the good names for the boxes	Card boxes, glue, gift papers, stapler, pairs of scissors, watercolours. The book	Handcraft	20:30-21:45	NB: Naming or dedicating the Memory Box helps the children develop an attachment to the box
	Recreation/ dancing and singing					21:45-22:30	
	Bedtime					22:30-6:30	

Day 3	Waking and Clean up					60:30-7:30	
	Tree of life 1						
	Main Objective: To create and explore a new story that is not only about pain and suffering but that also notes courage, survival skills, values and hope						
	Item	Specific Objective	Activity	Materials/Place	Method	Time	Remark
	Breakfast					7:30-8:30	
	Learning the metaphor of a tree	To help the participants understand why the tree is similar to their life	Teaching the participants the different parts of a tree and their functions	Forest/Tree	Teaching/brainstorming	8:30-9:30	NB: It advised to bring the participants to a big tree and stand around it
	Drawing a tree	To help each participant draw a tree that clearly shows the major parts of a tree.	The participants draw a tree on a new page	The book, Marker pens, pencils, watercolours	Drawing and writing	9:30-10:30	NB: The tree should clearly show the roots, trunk, the branches, the leaves, the flowers and fruits. It should cover the whole page
	Tea break					10:30-11:00	
	The origin of the participants	To help the participant identify the origin	The participants name each of the roots by the name of the relatives of the parents'	The book, Marker pens, pencils, watercolours	Personal reflection and Writing	11:00-12:30	The Roots

			generation (dead or alive)				
	Their present	To help the children clarify the most important thing they are currently doing in their life	The participants name the different things and activities they are engaged at home, school and etc despite living with AIDS				<i>The ground/soil</i>
	Their strength (and weaknesses) in living with AIDS	To help the participants identify their strength (may reflect on the weaknesses to realise their strength)	The participants list the strength on the left side of the trunk (and the weaknesses on the right of the tree.This is Storm in the forest)				<i>The trunk</i>
	Lunch break					12:30-14:30	
	Tree of life 2						
	Main Objective: To build and acknowledge “a second story” about each child’s life. The second story consists of the skills, abilities, hopes and dreams of each child and the histories of these.						
	Item	Specific Objective	Activity	Materials/Place	Method	Time	Remark
	Their dreams/ambitions	To help the participants reflect on the dreams and ambitions	The participant name each branch of the tree by their dreams or ambitions	The book, Marker pens, pencils, watercolours	Personal reflection and Writing	14:30-17:00	<i>Branches</i>
	Support different people	To help the participants reflect and identify different support systems	The participants name each of the leaves by the name persons or institutions that help them towards their dreams or ambitions				<i>The leaves</i>
	Awards and gifts	To help the participants reflect and appreciate the different awards, gifts and which they have received from others	The participants name the different fruits by the name of different awards, gifts etc received from different support systems				<i>The Fruits</i>
	Sports/games	To help the participants to Relaxation	Participants to play in groups	Football and netball, volleyball balls, skipping ropes, personal sports equipment in the volley ground	Playing	17:00-18:30	NB: The activities should not be too intensive and creativity should encouraged
	Dinner and cleaning up					18:30-20:30	
	The forest and the storms and Retelling their stories	To help the participants retell their stories to their fellow participants	The participants are divided into groups of five to six and share what they have drawn in their books	Books	Buzz groups	20:30-21:45	NB: the staff should be available to moderate the group. Members should only provide positive/praise feedback

							to each other especially on the different efforts the participants are putting in to positively live with AIDS
	Recreation/ getting a secret friend/Music	To help the participants get a secret friend to present a gift on the last day	The names of the participants are written on a small piece of papers that are then folded to hide the name. The pieces of the paper are thrown on the table at random. Each is asked to pick one of the papers	Pieces of paper, pens or pencils/table	Recreation	21:45-22:30	NB: The participant should not reveal the name until the last day when the will present a gift to the secret friend
	Bedtime					22:30-6:30	

Day 4	Waking and Clean up					60:30-7:30	
The Hero book							
Main Objective: To help the children find solutions to the personal and social challenges they face							
	Item	Specific Objective	Activity	Materials/Place	Method	Time	Remark
	Breakfast					7:30-8:30	
	Who am I?	To help the participants identify who they are when telling their story	Participant s each describe who they are by drawing their own face on a new page in the book, writing their name, age, origin etc as the first step to a story about oneself	Pieces of paper, pens or pencils/table	Drawing and writing	8:30-10:30	NB: The drawing does not need to be professional or complicated. Everyone is able to draw his or her face
	Who is my hero?	To help the participants identify and acknowledge their hero	The participants each describe who their hero/s is by drawing them and mention some of the things they receiving from those heroes	Pieces of paper, pens or pencils/table	Drawing and writing		
	The Difficult moments	To help the participants describe the most difficult moments in their lives	The participants describe by writing and drawing symbols of images of the most difficult moments in their lives.			10:30-11:00	NB: The participants are encouraged to describe and narrate difficult moments
	Counselling (group or individual) break	To provide 'on the spot' counselling for a participant who may need to reconcile their difficult situation	Counselling for some participants who would need individual or group who may need attention from staff/facilitators	Counselling room or place	Counselling	11:00-12:00	There may be some children who could have a posttraumatic reaction when sharing their challenges/ difficulties.

Encouragement from fellow participants	To help participants write some word of encouragement in fellow participants' books	Each participant draws his or her face on a new page in the book. The other participants write words of encouragement around the face of the owner of the book	Pieces of paper, pens or pencils/table	Drawing and writing	12:00-12:30	NB: the participants should the most encouraging words only
Lunchtime					12:30-14:30	
The greatest achievements in living AIDS	To help the participants identify one problem and show how they solved it to show their growth from a point in life to the other	On a new page, each participant draws an event that was the hardest and draws how each solved the problem	Pieces of paper, pens or pencils/table	Drawing and writing	14:30-17:00	NB: The participants should include the dates of the event
My community support system	To help the participants identify the different close social systems from whom they get support	Each participant draw different community systems such as school, church, family, sports team etc and briefly narrates how he or she interacts through different roles	Pieces of paper, pens or pencils/table	Drawing and writing		NB: This should only include those support systems are easily accessible to the participants
Sports/games	To help the participants to Relaxation	Participants to play in groups	Football and netball, volleyball balls, skipping ropes, personal sports equipment in the volley ground	Playing	17:00-18:30	NB: The activities should not be too intensive and creativity should encouraged
Dinner and cleaning up					18:30-20:30	
Ambitions	To help the participants reflect on their achievable ambitions in a given time frame	On a new page, each participant draws (or chooses some pictures from a variety of magazines, cut the pictures carefully and sticking them in the book) some achievements in social relationships and career and briefly write their description	A variety of magazines of popular and successful individuals. Glue, pencils, pens, a pair of scissors		20:30-21:45	NB: They should include the age and date when they would achieve that
Recreations and Retelling their stories	To help the participants retell their stories to their fellow participants and give and receive comments of achievements	The participants are divided into new groups of five to six and share what they have drawn and written in their books. They could write or draw positive comments and the owner of the	Books	Buzz groups	21:45-22:30	NB: the staff should be available to moderate the group. Members should only provide positive/praise feedback. The staff are free to

			book could write or draw comments of appreciation				comments too
	Bedtime					22:30-6:30	

Day 5	Waking and Clean up					60:30-7:30	
Making a will							
Main Objective: To help the participants learn how to write a Will							
	Item	Specific Objective	Activity	Materials/Place	Method	Time	Remark
	Breakfast					7:30-8:30	
	What is a Will?	To help the participants understand the importance of a Will as part as part of treatment and care in Palliative Care	Participant s are divided into 5 to 6 groups to discuss the following: <i>If you happen to be bedridden, why would you ask someone to keep your new Memory box with its memory workbook inside?</i>	Flip charts, marker pens and stickers	Buzz groups and presentation	8:30-10:30	NB: The facilitators should reinforce the value of safely keeping the Memory Box and its contents when the participant is very sick and in the events of their deaths
	Making the Will	To help the participants make a Will for their Memory box and its content	On a new page, the participants draw a picture or symbol of a person or persons who will care for the Memory Box and its contents in case the participant is very sick or died. Each participant should write the name and the residence of the person in the drawing.	A Memory box, the book, pencils, pens and maker persons	Drawing, writing and signing	10:30-11:30	NB: The executor is the PASADA (Coordinator) and the witness should be one of the staff or facilitators
	Preparation for the graduation	To help the participants prepare a gift (organised by PASADA) for their secret friends and presentation from the children and staff	Each participant is given a small gift to give to his or her secret friend. The certificates ready for presentation during lunch	Gifts, certificates Music	Celebration a	11:30-12:30	NB: The participants are encouraged to describe and narrate difficult moments
	Graduation and lunch	To celebrate	Each participant to present a gift to a secret friend and receive the Memory Work therapy graduation certificate			12:30-15:30	NB: Other members of staff from the Palliative Care Department could be invited to acknowledge the achievements of the participants